



**American Cleft Palate–  
Craniofacial Association**

1504 East Franklin Street, Suite 102  
Chapel Hill, NC 27514 USA

TEL 919.933.9044  
FAX 919.933.9604

[www.acpa-cpf.org](http://www.acpa-cpf.org)  
[info@acpa-cpf.org](mailto:info@acpa-cpf.org)

## Support for Individuals Affected by Cleft Lip and Palate

Cleft lip and cleft palate affect more than 7,000 individuals in the U.S. each year, leaving many people searching for support from others who understand their situation. The American Cleft Palate-Craniofacial Association has compiled a list of support resources to help individuals and families affected by cleft lip and palate connect with each other. Each organization, group, or individual listed below is responsible for their own content.

### National Support Resources

***American Cleft Palate–Craniofacial Association***

Supports parents and adult patients by email and phone by answering questions about cleft lip and palate and other craniofacial anomalies. Also provides recommendations to ACPA Approved Teams, distributes free educational publications, and annually awards college scholarships and scientific research grants.

1504 East Franklin Street, Suite 102  
Chapel Hill, NC 27514  
800.24.CLEFT (242.5338)  
[www.cleftline.org](http://www.cleftline.org)  
[info@cleftline.org](mailto:info@cleftline.org)

***Ameriface/Cleft Advocate***

Provides general information and networking, as well as advice for people who are fighting insurance denials for their medical care. Has the Pathfinders program, an outreach network that helps families find answers based on local services and experiences, and a state resource guide.

Post Office Box 75112  
Las Vegas, NV 89136  
888.486.1209, 702.769.9264  
[www.cleftadvocate.org](http://www.cleftadvocate.org)  
[Debbie@cleftadvocate.org](mailto:Debbie@cleftadvocate.org)

***FACES – The National Craniofacial Association***

Provides support to people with craniofacial differences through newsletters, information packets, and financial assistance for non-medical costs.

Box 11082  
Chattanooga, TN 37401  
800.332.2373  
[www.faces-cranio.org](http://www.faces-cranio.org)  
[faces@faces-cranio.org](mailto:faces@faces-cranio.org)

***National Foundation of Facial Reconstruction***

Provides comprehensive medical treatment, psychological counseling, research and education through the Institute of Reconstructive Plastic Surgery at NYU Langone Medical Center.

333 East 30<sup>th</sup> St, Lobby Unit  
New York, NY 10016  
212.263.6656  
[www.nffr.org](http://www.nffr.org)

***Specialized Training of Military Parents (STOMP)***

Provides international medical information and training to military families who have children with special needs.

6316 S. 12<sup>th</sup>  
Tacoma, WA 98465  
800.5.PARENT  
[www.stompproject.org](http://www.stompproject.org)

### Other Support Resources

***About Face:***

Provides information and support for individuals with facial differences and their families by linking people with similar experiences through a Peer Network. Offers a newsletter and publications.

[www.aboutfaceusa.org](http://www.aboutfaceusa.org)

The Cleft Palate Foundation is now

**ACPA Family Services**

800-24-CLEFT • [www.cleftline.org](http://www.cleftline.org) • [info@cleftline.org](mailto:info@cleftline.org)

**Children's Craniofacial Association**

CCA addresses the medical, financial, psychosocial, emotional, and educational concerns relating to craniofacial conditions.  
[www.ccakids.org](http://www.ccakids.org)

**Cleft Meetup**

An online message board helping to facilitate face- to-face meetings among people in their own local areas.  
[www.cleft.meetup.com](http://www.cleft.meetup.com)

**Craniosynostosis and Positional Plagiocephaly Support (CAPPS)**

Online support group and information for parents of children with craniosynostosis and positional plagiocephaly.  
[www.cappskids.org](http://www.cappskids.org)

**Crouzon Support Network**

Online group for individuals and families affected by Crouzon Syndrome and other craniofacial anomalies.  
[www.crouzon.org](http://www.crouzon.org)

**Friendly Faces:**

A resource for, and a network of, individuals with facial differences, parents, families, friends, and healthcare professionals.  
[www.friendlyfaces.org](http://www.friendlyfaces.org)

**Moebius Syndrome Community (through RareConnect)**

Hosted by patient advocates, this is a place where individuals affected by Moebius syndrome can connect with others.  
[www.rareconnect.org/en/community/moebius-syndrome](http://www.rareconnect.org/en/community/moebius-syndrome)

**Moebius Syndrome Foundation**

Provides information and support to individuals with Moebius syndrome and their families.  
[www.moebiusyndrome.com](http://www.moebiusyndrome.com)

**Pierre Robin Network:**

A network of families whose children have been diagnosed with Pierre Robin Syndrome.  
[www.pierrerobin.org](http://www.pierrerobin.org)

**"Teeter's Page"**

An online support and information source for individuals and families affected by Apert Syndrome.  
[www.apert.org](http://www.apert.org)

**Treacher Collins Foundation:**

An organization of families, individuals and medical professionals who are interested in developing and sharing knowledge and experiences about Treacher Collins Syndrome and related conditions.  
[www.treachercollinsfnd.org](http://www.treachercollinsfnd.org)

**Velo-Cardio-Facial (VCFS) Educational Foundation**

The VCFS Educational Foundation is a non-profit organization that provides support and information to individuals and families who are affected by Velo-Cardio-Facial syndrome.  
[www.vcfsef.org](http://www.vcfsef.org)

**International Support Resources**Australia**Cleft Pals**

[www.cleftpalsnsw.org.au](http://www.cleftpalsnsw.org.au)

Canada**About Face International**

[www.aboutface.ca](http://www.aboutface.ca)

Ireland**Cleft Lip and Palate Association**

[www.cleft.ie](http://www.cleft.ie)

United Kingdom**Cleft Lip and Palate Association**

[www.clapa.com](http://www.clapa.com)

**Please contact ACPA Family Services for further information or for a referral to a cleft palate/craniofacial team.**